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ABSTRACT

Three pamphlets provide basic information on the care and education of children with osteogenesis imperfecta (OI) a lifelong liability to fractures due to imperfectly formed "brittle bones." The first brochure, a guide to eduction for children with OI, addresses the importance of attitudes, the value of early education, public school enrollment, due process, individualized education programs, classroom adjustment, and college attendance. The second brochure describes the development and functions of the Osteogenesis Imperfecta Foundation, Inc., a voluntary national health organization. The final pamphlet provides suggestions for the care of babies and children with OI and answers questions about such aspects as home management, clothing, food, first aid, and day to day care for chldren wearing a body cast. Information on helpful equipment and toys concludes the pamphlet. (CL)

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A Guide to Education for Children with Osteogenesis Imperfecta

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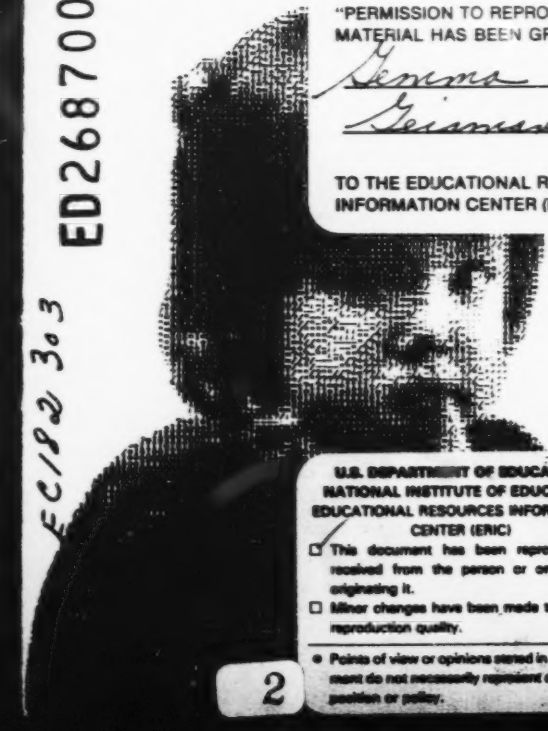

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ACKNOWLEDGEMENT

OIF, Inc. wishes to thank Rosalind James of Eastport, New York who researched and authored this handbook. Mrs. James is a former president of the New York Chapter of OIF, an area coordinator, and a member of the Board of Directors of OIF, Inc. She is the mother of an OI son, Stuart.

For a number of years, Mrs. James has taken a keen interest in the problems associated with mainstreaming handicapped children, and particularly OI children, into public schools. She has attended a number of workshops on the subject and currently serves on the Committee on the Handicapped in her local school district.

We hope that this pamphlet will be a helpful guide to parents as they attempt to obtain the best education possible for their OI child.

Gemma Geisman
Executive Director - OIF, Inc.

Cover Design: Bob Bruce

A GUIDE TO EDUCATION FOR CHILDREN WITH OSTEOGENESIS IMPERFECTA

INTRODUCTION:

Public Law 94-142 states that every handicapped child has the right to a free appropriate education at the expense of its local school district.

Parents need to be aware of their child's right to receive a full education in "the least restrictive environment." Lease restrictive environment means that a handicapped student should be educated in a regular classroom environment, if at all possible, with appropriate supportive supplementary assistance where necessary. This is popularly referred to as mainstreaming, and is particularly appropriate for children with osteogenesis imperfecta (OI), since they are usually of average or above average intelligence, and can benefit a great deal from the stimulation and social contact of a regular classroom situation.

One of the basic problems that faces the child with OI is the architectural barriers encountered in public school buildings. Section 504 of the Rehabilitation Act 1973 provides that all programs supported by federal dollars must be architecturally accessible. With this provision, OI children who are partially or completely ambulatory or in wheelchairs, are now being mainstreamed very successfully.

We do recognize that some OI children are too frail to benefit from this academic experience. In these cases, the next "least restrictive environment" should be sought for them. In order of desirability this would be – a special school for handicapped children, home tutoring or a residential school. It should be noted that home tutoring is considered to be one of the least desirable means of educating a child as it deprives them of any social contact. For those who feel a school for special

education is more suitable for their child, it is important to seek a school with classes for physically handicapped children, which are separate from the classes for mentally or emotionally handicapped children. Just as a deaf child would not benefit from attending a school for the blind, equally, a physically handicapped child will not benefit from attending a school designed to help mentally handicapped or emotionally disturbed children.

OUR ATTITUDE IS IMPORTANT

Going to school is a big step in itself for any child, but is particularly frightening for the OI child. Reassurance and strong support from parents is vital in order to make this a happy and successful experience. It is helpful for the child to be as self-sufficient as possible.

This is also a frightening experience for the parents. They need to recognize the importance of offering their child this valuable opportunity for academic growth and social development, which far outweighs the obvious risks.

Being well informed of your child's rights will also give you added confidence when approaching your school (see Sources of Information).

WHERE DO WE BEGIN?

Ideally, all school census takers should ask if there is a child with a handicapping condition in the household. However, parents should inform the school during the first school census taken following diagnosis, whether the question is asked or not.

Many of us are going to be the first to introduce a physically handicapped child into a particular local school, and this may require

a special effort and determination.

Regardless of whether a child is entering the public school system at kindergarten, is transferring from a special school or from home tutoring, the approach in terms of attitude is basically the same.

It is important to approach the school with a positive and pleasant attitude. Reassure the school officials that they can have a fragile child and that he/she will be able to manage very well with a minimum of additional attention. Emphasize your child's strengths rather than his shortcomings.

Although we recognize that the law ensures your child's right to a public school education, a pleasant approach toward the school officials, rather than an overly demanding attitude, can often be much more effective. If, however, the school officials are totally uncooperative, a stronger attitude may be needed. (See Due Process).

NURSERY SCHOOL.

Attending nursery school is a very valuable experience for the OI child. It helps develop self-confidence, teaches them to trust other adults to lift them, and provides them with an excellent opportunity for social contact with other children.

Often, nursery school programs at special education schools are designed for the mentally handicapped or emotionally disturbed children. Sometimes private regular cooperative nursery schools are reluctant to accept physically handicapped children, whereas a church-run nursery school is more willing to accept them. You may wish to offer to accept all responsibility for any fractures that may occur. Do offer lots of literature on OI, and give them a telephone number should an emergency arise. It is preferable not to attend the program itself, since your child needs

to develop confidence in his ability to be without you for a few hours each week.

When your child is ready for kindergarten, it helps a lot to be able to let them know that he/she has already attended a regular nursery school program successfully.

ENROLLING IN PUBLIC SCHOOL.

The following pertains to any student entering public school; whether it is at the kindergarten level, or being mainstreamed into a higher grade.

Contact the school superintendent for an appointment to discuss your child's admission to school. Be willing to discuss your child's handicap, and, if necessary, to explain osteogenesis imperfecta. If your child participates in a clinic at a large hospital, a letter from the doctor advising the school that the child is able to attend a regular school program is most helpful. Otherwise you might ask your local doctor for his support. Brochures and literature available from OIF, Inc. will also be most helpful.

Each school has a team responsible for making recommendations to the Board of Education on the placement of the handicapped children in their district. This may be called the Committee on the Handicapped, Planning and Placement Team, Educational Evaluation Team or some similar name.

Request to meet with this committee to discuss their recommended placement for your child. Once again, a calm reassuring attitude on your part is invaluable. Take your letter from the doctor and OIF literature with you. Emphasize that many OI children attend public school.

A school with many steps can often be made architecturally accessible for a wheelchair student at relatively little cost by the addi-

tion of a few wooden ramps and other minor modifications. However, if accessibility is a severe problem in your local school, it might be preferable for your child to attend a *near-by* school which is more architecturally suitable. The tuition would be the responsibility of the local school district if it approves this alternative. No child, however, should have to travel an unreasonable distance to attend school.

Transportation to and from school must be provided by the local school district. If there are several handicapped students in the district, the school often has a mini-bus. However, should your child be the only one, the school station wagon is often a fine alternative.

Other recommendations you might offer to facilitate your child's attendance would be:

1. Arrange for an ambulatory OI child to change classes a few minutes before the bell rings. This prevents unnecessary physical contact in crowded halls.
2. A separate set of books to be kept at home for the student's use. This would avoid the need to carry heavy books for home work.
3. A urinary bottle be kept in the bathroom for the use of a boy in a wheelchair.
4. Special arrangements often have to be made for gym classes. A child should participate in the regular gym program to the fullest extent possible.
5. Once a child has reached second grade, other classmates are often capable and usually very willing to assist the wheelchair student get around.
6. If you and your child have special equipment for accomplishing some necessary activity, you can offer to provide same for use in school.

The school will want to test your child. This evaluation is given to every handicapped student, and your permission is required. The Committee will notify you in writing of their proposed placement of your child, and your approval is required. If you do not agree with the recommendation, you must notify the Board of Education within ten days. (See Due Process).

DUE PROCESS.

If you are unable to reach agreement with the school on the placement of your child, a specific procedure is available to you, and this is called "Due Process."

This is a procedure that is guaranteed upon request if a disagreement arises concerning identification, assessment or placement of a child. You will be notified of this process in writing when the school advises you of their recommended placement for your child.

If you feel that you need advice or assistance in order to take these measures, contact the Regional Associates at your State Department of Special Education. The Department of Special Education is most anxious that as many handicapped children as possible receive the benefit of a public school education and will make every effort to help you obtain this opportunity for your child.

Many areas also have advocacy groups who will provide information and personal assistance to a family in this situation. Some of these groups are listed in the Yellow Pages under Social Service Organizations.

INDIVIDUAL EDUCATION PROGRAM (IEP).

An Individual Education Program is a written plan, developed by the Committee on the Handicapped which describes the educational

program for your child for one school year.

This Program shows your child's current educational level, short and long term goals and any special means or needs to achieve these goals. It also includes any special related services your child will require: remedial reading, speech therapy, special gym program, etc.

Again, your signature of approval is required on each IEP.

IN THE CLASSROOM.

Now that your OI child is in the public school, here are a few suggestions for making the adjustment easier. Educate the teacher about OI. Offer brochures and pamphlets available from the Osteogenesis Imperfecta Foundation. Reassure him/her that should fractures occur, they should not feel at fault, emphasizing that the benefits gained by the child's participation in a regular school program far outweigh the possibility of a fracture, which would occur wherever the child may be.

Ask the teacher to explain to the other children, when the OI child is not present, about the child's handicap, and be willing to answer any and all questions they may have.

Knowing and accepting the child's limitations, the OI child should then be accepted equally by the teacher without special favor or attention.

ATTENDING COLLEGE.

In most cases, the only deterrent facing the OI child in choosing a college is accessibility of both the learning and living accommodations.

Due to Section 504 of the Rehabilitation Act, state colleges are often the better choice since

they are now rapidly becoming totally accessible in accordance with this law.

A visit to any considered college, whether state or private, is imperative, in order to judge the degree of accessibility for yourself.

SOURCES OF INFORMATION

State Department of Education
Office for Education of Children with
Handicapped Conditions
State Capital

Mr. Edwin W. Martin
Assistant Secretary for Special Education and
Rehabilitative Services
Donohoe Building
400 6th Street S.W.
Washington, D.C. 20024

Osteogenesis Imperfecta Foundation, Inc.
632 Center Street
Van Wert, Ohio 45891

Closer Look
P.O. Box 1492
Washington, D.C. 20013

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FOR MORE INFORMATION

on OI, copies of publications, information on parent groups, or contact couples nearest you, or to make tax deductible contributions, write to:

OIF, INC.
MRS. GEMMA GEISMAN
P.O. BOX 838
MANCHESTER, NH 03105
(603) 623-0934

OTHER OI PUBLICATIONS:

What is OIF?
Care of an O.I. Baby and Child
I Have O.I. but Can . . .
Breakthrough (a quarterly newsletter)
Selected medical monographs
Literature list available.

Published by Osteogenesis Imperfecta Foundation, Inc.

WHAT IS OIF?

Osteogenesis Imperfecta means a lifelong liability to fractures due to imperfectly formed "brittle bones".

While the exact number of persons affected with OI in the USA is unknown, the best estimate suggests a minimum of 10,000 and possibly as many as 30,000 persons are affected.

Despite numerous fractures resulting in pain, restricted activity and diminished growth, many adults with severe forms of OI lead productive and happy lives. However much needs to be done to assist all OI sufferers through public education, research and support for special management clinics.

WHAT IS OIF?

The Osteogenesis Imperfecta Foundation, Inc. is the only voluntary national health organization dedicated solely to alleviating problems associated with OI.

HOW DID OIF, INC. BEGIN?

In April of 1970, a small group of parents from various parts of the nation met in Chicago to discuss OI and its problems. At that time they banded together to stimulate public and professional interest to discover effective treatment for OI and through research understand the basic chemical defects in the tissues leading to OI. This was the beginning of OIF, Inc.

WHAT ARE THE FOUNDATION'S PURPOSES?

To gather together available knowledge concerning OI; to share that information with OI patients, their families, members of the medical profession and other interested persons; to initiate, encourage, and offer support for OI research.

WHO ARE THE MEMBERS AND OFFICERS OF THE OIF, INC.?

Parents of OI children and adult OI patients comprise a majority of the membership. The Executive

Board and members of the Board of Directors are nearly all parents or patients actively involved in the work of the OIF, Inc. But anyone interested in the welfare of OI patients is encouraged to become a member.

HOW IS THE OIF. INC. OPERATED?

The policies of the OIF, Inc. are determined by the Board of Directors. An Executive Board of the officers executes these policies. The OIF, Inc. is a non-profit, voluntary agency, and depends on membership dues, contributions from individuals, corporations, organizations and philanthropic foundations for its support. Because of the great need for research, education and service, the OIF, Inc. also hopes to receive financial assistance from broad segments of the public.

WHAT IS OI?

OI is a group of heritable disorders which have in common a lifelong tendency to fractures. Other features in some but not all patients include blue sclerae (whites of the eyes), early onset hearing impairment, loose joints, short stature, discolored fragile teeth and excessive perspiration.

Some individuals have numerous fractures at birth (congenita cases) while others may not have fractures till later in infancy or childhood (tarda cases).

IS OI HEREDITARY?

OI is always heritable, i.e. able to be inherited. As far as we know, OI is always due to a fault in the chemical units of the heredity (genes). Because there are several different patterns of heredity, OI is not always manifest in each generation of a family. Furthermore the chance that OI will recur in the family once one family member manifests the trait, varies depending on the pattern of inheritance for OI in that particular family.

OI patients or their parents should request genetic counseling to obtain a better understanding of the likelihood of OI recurring in their family.

WHAT CAUSES OI?

The cause of the various types of OI appears to lie with faults in the genes. The evidence to date suggests that the genetic defects lead to insufficient production of collagen or production of faulty collagens in bone and other tissues. Collagen is the fibrous protein which is encased in mineral and gives bone its tensile strength. A deficiency or weakness in bone collagen would lead to bone fragility.

The defects in bone chemistry and tissue production of collagen proteins, is being systematically explored by research groups around the world.

WHAT MEDICAL TREATMENTS ARE AVAILABLE TO OI PATIENTS?

Until recently, the only effective medical treatment for OI patients was a surgical procedure known as "rodding" or fragmentation surgery, implemented to correct the deformities that resulted from numerous fractures. Today, many hospitals and medical cen-

ters have opened OI clinics in an attempt to treat all of the symptoms, including the biochemical, physical, psychological, dental, and hearing problems. Most of these studies are relatively new and still in the experimental stages.

WHAT ABOUT OIF PUBLICATIONS?

A newsletter, **BREAKTHROUGH**, is published quarterly. It offers realistic ways of coping with OI and brings hopeful news concerning OI research and treatment to OIF, Inc. members. It is written by parents, patients, physicians, and researchers and edited by members of the OIF, Inc.

HOW CAN YOU HELP OIF, INC.?

You can join the rapidly growing number of persons who have banded together to pursue two main goals: To support research into the causes of OI both at the level of the genes and the tissues; To discover effective means of preventing and treating OI.

Many volunteers are needed to help locate OI patients, to organize local chapters and support groups, and to participate in fund raising activities.

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FOUNDED IN 1970

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Published by Osteogenesis Imperfecta Foundation, Inc.

CARE OF AN OSTEOGENESIS IMPERFECTA BABY AND CHILD

If your physician has just informed you that your new baby has been born with Osteogenesis Imperfecta (OI), you are overwhelmed with anxiety and concern about your baby's future. This is a difficult time for you to understand or absorb what your physcian has told you.

The purpose of this brochure is to help you understand your physician's explanation of this genetic defect and briefly tell you about some of the problems with which you will have to cope. An attempt is made to answer the questions most often asked by parents of OI children.

ACKNOWLEDGEMENTS

My sincere thanks to the many parents who have responded to my questionnaires, to those who have so faithfully brought their children to the Osteogenesis Imperfecta Clinics at Shriners Hospital for Crippled Children, Chicago Unit, and to those who have kindly granted me permission to reprint photographs. Deep appreciation is especially accorded to each parent contributor for his or her part in this booklet.

I wish to express my deep debt of gratitude to Clive C. Solomons, Ph.D., Director of Orthopaedic Research, The University of Colorado Medical Center, Denver, and Edward A. Millar, M.D., Chief Surgeon, Shriners Hospital, Chicago, originators of the research project in osteogenesis imperfecta.

Frances M. Dubowski, R.N.
Silver Lake, Wisconsin
1978

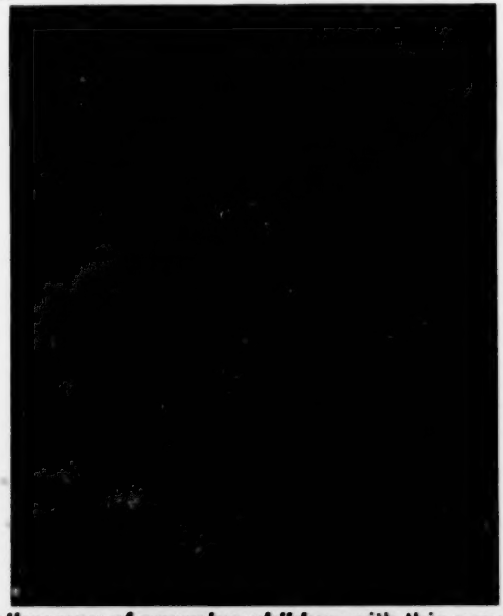
(Cover photo courtesy the Detroit News and used with permission.)

CARING FOR THE BABY AND CHILD WITH OSTEOGENESIS IMPERFECTA

Definition of Osteogenesis: The formation of imperfect bone. The OI child has bones so fragile that a bone may fracture with little force.

There are two classes of OI: **Congenita:** The diagnosis is obvious at the moment of birth. The infant may be born with as many as 50 - 100 fractures. Some of these fractures may have occurred within the womb. These children may experience recurring fractures, bone deformities, and stunted growth. Many children depend on a wheelchair, walker or other apparatus to help them move about.

Tarda: This type is not always recognized at birth. These children have a near normal appearance. Fractures may occur days, months, or even years later.



Another way of grouping children with this genetic defect is according to the degree of the physical involvement. **Severe:** These children have multiple and frequent fractures with severe deformities of the arms and legs. Blue sclera (whites of eyes are blue) may or may not be present. Teething is delayed and teeth and roots will be smaller. They are widely spaced and yellowish-brown in color. Good dental condition is uncertain. The face has a triangular shape with a wide forehead and narrower chin. Body is short and deformed, corresponding with the severity and number of fractures. The greater the number of fractures incurred, the shorter the children will be. The children are barrel-chested, having an enlarged rib cage. They have a looseness

of joints. Many have a tendency to be very warm and to perspire excessively. Some have a very high-pitched voice. **Moderate:** These children will have fewer fractures than the severe group. They may or may not have blue sclera. Some will experience delayed growth. They will also have poor teeth. The face will be normal or near-normal in appearance. Body size will be influenced by the severity and number of fractures. Fracturing of the legs will be more frequent than fracturing of the arms; therefore, the deformities will be greater in the legs. They will also have a looseness of joints.
Mild: These children have few fractures and the defect may not be recognized until they participate in sports. Most frequent fracture areas are the collar and ankle bones. This group of children may be shorter, but the defect may not be readily identifiable by laypersons. The children in all three classifications may develop curvatures of the spine and loss of hearing. The number and frequency of fractures are reduced in the teenage years but the deformities remain.

COMMON QUESTIONS ABOUT OI:

1. How common is OI?

There are approximately 30,000 cases of OI in the United States. It has been reported in all nations of the world. It is known to be the most common of the inheritable defects. OI is definitely known to be hereditary, but medical researchers are still working to develop a test to determine how or by whom the defect is transmitted.

2. What problems will an OI baby have?

An OI baby has a tendency to be warmer than the

normal baby. Some may consistently run a slightly elevated temperature without any signs of an infection. Extreme thirst may be evidence of an increase in their temperature. An adequate supply of water and other liquids should be provided at all times. They willingly drink more liquid than other children. They may have nosebleeds and show bruises at any area of the body with little or no provocation. Therefore, a parent must be careful when handling the child because any quick movement or sudden bumps could result in bruises or fractures. Bruises mean what are commonly described as "black and blue spots." Constipation can be a problem with some OI children. There is a need to encourage consumption of fruit and fruit juices — in addition to a good basic diet — to establish good bowel habits.

3. Can the OI baby live at home?

Yes, your baby belongs with you and your family. Let all members of the family enjoy the child's arrival and hold the baby gently. Teach your family how to hold the child in a way to avoid fractures.

No two infants will be alike. Through gentleness you will learn how much handling your infant can tolerate. A firm pillow, a well-padded piece of plywood, or a baby carrier can serve to transport the baby from room to room. A playpen (mesh type) used in any room provides a safe place to share the family atmosphere or social activities.

4. Can such a fragile baby be bathed?

Yes, and in time this will be a pleasure for both you and baby. First, assemble all the necessary articles needed so you can avoid looking for an item in the middle of bath time. A padded countertop, a table adjacent to a sink, or a plastic bath basin on the kitchen table serve as comfortable areas. The infant may be lathered while lying on a towel or sponge pad. Then -- supporting the child's head, back and buttocks -- lift the baby into the sink or basin, in which there should be no more than two inches of water. Ease the child onto the buttocks and, with your free hand, rinse off the lather. When (and in areas where) weather permits, a bath may be enjoyed out-of-doors, using the same techniques

and equipment. An older child may enjoy a bath while sitting in an open mesh plastic laundry basket. Place the laundry basket inside the bathtub. The basket provides added safety and security and can easily be lifted into and out of the bathtub.

5. What type of clothing should an OI baby wear?

Clothing fabrics should be lightweight, cotton stretch, absorbent and non-constricting. Avoid ribbons, buttons, pockets and ruffles. Zippers should replace buttons. Clothing should completely open down the front or back. In applying your child's diaper, place your hand under the child's buttocks, lift the baby and -- with your other hand -- place the diaper under the child. Never lift the infant by the ankles because this may cause a fracture of bones in the legs and feet.

6. Will an OI baby eat the same foods as other children?

Yes, most OI feeding parallels that of normal infants. While feeding formula, cradle your baby on a firm pillow with a comfortable amount of pressure. If a painful fracture prohibits holding the child, then a lightweight plastic bottle may be propped beside the child when lying in a crib or padded area. The older child may be placed in a portable seat-carrier - the type used for toting from place to place -- with a soft strap across the child's middle. Any chest constriction could fracture the ribs. For a child in a spica cast (plaster cast covering leg, hip and abdomen), the upper portion of the body should be slightly elevated or the child may stand in a table-type walker. The pre-schooler or school-age child might prefer to sit in a small wheelchair and feed himself. Because an OI child may have poor teeth, the use of a blender-type appliance is useful in preparing meals. Many are picky and slow eaters, thus small and frequent feedings should be encouraged. An increased amount of liquids, calories, and protein should be included in their diet when there is excessive perspiration. OI children are always thirsty and should be allowed to drink as much as they want. They need only normal amounts of calcium, but generally dislike milk. It is advisable to either add flavoring to milk, serve ice cream and puddings, or use milk in cooking to contribute to their daily intake. There is no evidence that any specific dietary substance is particularly helpful with OI.

7. How does one know when an OI baby has a fracture?

In most instances, your child will cry out. There may be excessive or prolonged crying because of pain. The baby will avoid movements of the fractured arm or leg. Sometimes you may even hear the fracture when it occurs.

8. What can be done at home when a fracture occurs?

Comfort the child with your presence. Try to locate

where the fracture has occurred. Hold the child only if the child allows it. Place a cold compress on the fractured area if the child tolerates it. If an arm is fractured, the use of a sling made from a large handkerchief may be helpful. If a leg is fractured, support the leg with a padded board or magazine. Frequently, a child will self-splint a fractured arm by holding it firmly against the body for several days while healing begins. Many fractures heal without the application of plaster casts, but this must be determined by your physician. Gently wrap your child in a suitable coverlet and transport the child to your physician or hospital. If a plaster cast is applied to an arm, additional support should be given by using a triangle-type sling. If a plaster cast is applied to a leg, place a padded board under the buttocks and legs to ensure that neither leg dangles. The possibility exists of fracturing the other leg in the process if care is not taken. Dangling can also cause a fracture above or below the area of the cast.

9. What are the day-to-day problems of caring for a child wearing a body cast?

Urine on the cast causes crumbling and destruction. Do not get it wet. A boy's penis may be directed into a tube, and urine flow directed away from the cast. With baby girls, cast care becomes a greater challenge. At all costs, avoid diarrhea! Disposable diapers are a big help. Using the overnight diaper size, detach the back third from the plastic liner and fold it down. Place this part under the buttocks. Place one-half of a sanitary napkin under the buttocks -- the remaining half over the front -- for greater absorption. The front edge of the diaper should be folded one-inch over and inserted into the front of the cast opening. At night and nap time, use the toddler-size with a few variations. If the child sleeps on the tummy and, because of the cast cannot turn over alone, leave the buttocks exposed completely. This gives the back of the cast a chance to dry. Fold the top front of the diaper over an inch -- as in the daytime -- and insert it into the front opening of the cast. Then spread the rest of the diaper under the child's body. With a few small pillows, prop the crib mattress up at the head end, allowing the child to sleep on a slight incline, so the urine will tend to flow downward. Fold an old receiving blanket or some cloth diapers and place them underneath the cast so any moisture that did seep through may be absorbed by this padding instead of the cast. No matter what precautions you take, the cast may become damp and smelly. Washing the cast with various solutions has not been effective. For dampness, use an old-fashioned hair dryer with a soft hood. Cut two holes in the hood and slip on -- as you would a pair of plastic

pants -- with the regular head opening around the waist. Plan this drying period during a child's favorite television program time and enjoy it together. Check the heat level regularly. Bear in mind that as your baby grows, bladder and bowel management become a simpler routine.

10. What causes OI?

The causes of OI are not yet known. The results of medical research thus far indicate that nothing you or your husband did or failed to do at anytime during your pergnancy has anything to do with this condition. This genetic defect has been prevalent for thousands of years. Medical researchers are making some progress in learning about OI and these researchers hope to prevent this type of birth defect in the future. If this is your first baby, the question of the possibility of having another child with OI may be uppermost in your mind. You may discuss this thoroughly with a member of a hospital or medical school genetic staff. A geneticist is specially-trained in counseling parents about hereditary diseases. The geneticist will study your family and try to determine what the chances are of the defect repeating itself.

11. How can the family assist in caring for the OI baby?

First, your family must accept the OI child. Treat the child as you would any other child. Your baby has a normal mind and the chances for a productive life are good in our society. Encourage your child to develop any talent or ability that will provide a feeling of accomplishment. Include your child in all family activities. Give your child all the social and educational experiences you would give any child -- and subject your child to the same discipline and responsibilities as well. This will integrate the family and help your baby become a well-adjusted member of the family unit. Delegate duties to other members of the family and, if possible, hire help when the need arises. Take advantage of as many conveniences as you can afford, i.e., use disposable diapers, paper table products, and clothing that requires little care.

12. Aside from my family physician, where may I go for help?

There will be times in your life when you may feel the need for counseling on social, educational, and psychological problems. These special problems can best be handled as they occur. If your physician feels he/she cannot adequately guide you, then a visit to or a telephone call to the parents of another OI child may be supportive. The Osteogenesis Imperfecta Foundation has information for families and physicians. The Foundation is comprised of families with OI children and members who are concerned with the welfare of OI patients. The Foundation gathers and shares information on

treatment past and present, helpful equipment and new ideas from parents on the care of an OI child. The Foundation also distributes a quarterly newsletter -- "Breakthrough" -- which informs members about the latest research developments. You are welcome to communicate with the Foundation. You will be communicating with persons who have already experienced and dealt with many of your concerns and with the search for a cure. (See listing, back cover.)

13. What should I tell my child if hospitalization is a must?
Tell your child the truth about being there. Give an honest explanation of the need for a cast application or surgery and the time needed for healing. Give your child the assurance that you will visit regularly whenever possible. Never talk in a whisper while in your child's presence. Children can "read" tired expressions on parents' faces. Technical words about an illness tend to frighten children. Tell your child that some discomfort is expected and that it is all right to cry when a procedure is painful. Parents may act as liaison between the hospital staff and the child, particularly when the child requests information about himself.

14. How can parents be of help to the hospital staff?
Most hospitals need a detailed history of the child's likes and dislikes in foods, home feeding schedule, allergies and medication. From this history they can adopt a schedule similar to the one at home. Talking openly with a social worker can help you remain composed and able to understand the need for a temporary separation. One note of caution: Hospital personnel and teachers are legally bound to report any suspected cases of child abuse. A child with a history of several fractures and easy bruisability (black and blue areas) -- as in the case of OI children -- may become a suspected case of child abuse. Hospital personnel and social workers may find it necessary to question parents, relatives, and

neighbors about the injury. Voluntary information could materially help this situation and your tolerance is needed.

15. How can we help our child at home?

As your child progresses, it is imperative that you let the child do things. Permit scooting or crawling to reach toys, etc. Your child needs your assistance, but not every minute of your time.

The best advice to the parent of the severely affected child is to take one day at a time. Crawling, walking, toilet-training, and teeth formation will be delayed so eating habits will not compare with those of other children. The child may roll before crawling; may prefer to scoot on the back while using the arms as "propellers." In activities, your child may not compare with your other children but -- if you allow the OI child the same freedom -- mobility will be developed in time. OI youngsters are usually happy and bright and may manipulate you and the entire family if you allow this to happen. Take the time to reassure your other children and your spouse that although they do not have as much of your attention, they have your love. The entire family must be willing to share in some of the care of your OI child, but they need to know that you love them just as much. Finally, do not keep this defect a secret. Be open about it. Explain it to your family and friend Your relatives and friends will be far more considerate and helpful when they understand the fragility of your child, the additional care needed and some general knowledge about OI.

EQUIPMENT FOUND HELPFUL TO OI PARENTS

1. **Buggy** with suspension springs,
2. **Crib** -- padded on all four sides to prevent arms or legs from falling between the rails,
3. **Small plastic** air mattress or sponge rubber pad large enough for baby to lie on in tub or sink,
4. **Carrier-type seat** with safety strap for placement on auto seat, which can be fastened by auto safety strap,
5. **Play pen** (mesh type) for use in any room in the home (padded top/bottom rails),
6. **Car platform** over back seat which extends to support a long leg or body cast; this is ideal as a bed when a long trip is planned,
7. **Crawl-a-gator** -- can be homemade -- a platform close to the floor of padded plywood on 4 casters so the child may propel

from room to room by use of arms or legs.
8. Wild Rider (by Marx Toys) -- a hand-operated car for those who cannot operate the pump-type tricycle or car.
9. Electric wheelchair for mature OI child/adult needing transport to and in school or place of employment.
10. Porta-Chair -- which clips to an ordinary table.
11. Practical toilet seat pattern -- Australian OI publication "Even Break," Vol. 1, No. 2 (all issues available from OI Foundation; see back cover for address).

TOYS FOR GROWTH

Bath Play -- rubber toys that float, colored sponges.
Crib toys -- Smoothly sanded wooden rings or plastic bracelets can be attached to an elastic band fastened to the top of crib. Small bells securely tied to this band so that they tinkle when rings are grasped.
Squeeze toys -- rubber or plastic squeeze toys especially animals with feet, ears, snouts and tails that may be grasped are useful. The sound mechanism in these toys, if there is one, should be vulcanized permanently in place.
Cuddle toys -- the infant, soft-cuddle toys that are lightweight and yielding to the touch. The firmly packed variety should wait until the child is older.
Music -- imitations of familiar sounds -- chug-chug of an engine, zoom of a plane; children enjoy music, although they may be more fascinated by watching the record turn.
Common household objects may be more fascinating to the baby than conventional toys. Plastic cups, toy dishes, etc., may be favorites, particularly if the child is able to put some inside others. Plastic cookie-cutters.
Dolls -- small 6-8 inches long, made entirely of rubber, without hair or moving eyes. A few pieces of cloth to wrap the doll will serve as a wardrobe; an intricate wardrobe may be difficult to manage.

Soft balls to roll, soft plastic blocks, for construction and wrecking. Add different shapes of blocks to the original unit-size set, such as cylinders, triangles, and arches.
Small books with plenty of pictures of familiar things such as trucks, telephones, animals to identify. Listening is an art and needs to be tied to a familiar activity, such as looking around for where sound comes from.
Quiet toys -- as new abilities seem to emerge, a new type of material may be offered; sewing cards, blunt toy-type table blocks, toy logs, color cubes, puzzles, bits of yarn, scraps of material (fabric).
Discussion of make-believe and fantasy is very real to a child and should be treated with respect.
Homemaking -- shoebox doll house with miniature furniture (select without sharp edges).
Miniature forts, barracks, soldiers, sailors, cowboys, animals and small corrugated boxes for creating a farm, city, or army base.
Handicrafts -- finger-painting, coloring books, simple jigsaw puzzles.

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